

# **Treating Lyme Disease**

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# Lyme Disease and Antibiotic Therapy Treatment

Lyme disease is caused by infection with *Borrelia burgdorferi*, a type of bacteria called a spirochete. In the eastern U.S., the infection is transmitted by the bite of a black-legged tick, *Ixodes scapularis*, commonly known as the deer tick. Left untreated, this is a serious disease that can affect the skin, heart, nerves or joints.

Lyme disease can be effectively treated with antibiotic therapy for 10 days to four weeks. However, there is disagreement between those who advocate for long-term antibiotic treatment (lasting months or years), and medical experts – including the Infectious Disease Society of America, the Centers for Disease Control & Prevention (CDC), and the National Institutes of Health (NIH).

## **Emergence of Lyme Disease in Vermont**

The deer tick, which carries the bacteria that causes infection with Lyme disease, has become the most frequently found tick in Vermont. As the number of deer ticks has increased, so have the number of reported cases of Lyme disease.

Lyme disease was first recognized in the state in 1988, and a few cases were reported to the Vermont Department of Health each year. In 2005, cases started to increase steadily, reaching an all-time high in 2013 with almost 700 reports of people who were likely exposed in the state. Historically, most of the reported cases have been in people who live in southern Vermont, but illness has been reported from all areas of the state.

# Accepted Treatment Guidelines vs. Long-term Antibiotic Therapy

Advocates for long-term antibiotic therapy believe that this is the appropriate treatment for Lyme disease. They say that Vermont physicians will not treat them appropriately for fear of sanctions if they prescribe treatments that are not recommended in the accepted treatment guidelines.

There is no question that a significant number of people who get Lyme disease will have ongoing symptoms even after being treated according to accepted treatment guidelines. At the root of the controversy over treatment is the disagreement about whether Lyme disease can be a chronic disease that requires long-term antibiotics to treat. Despite some patients' persistent symptoms, current research does not support the assertion that Lyme disease can manifest as a chronic infection, and clinical trials to date have not found that long-term antibiotics improve outcomes in people with Lyme disease.<sup>1</sup>

According to the Infectious Disease Society of America:<sup>2</sup>

"Using antibiotics for a very long time (months or years) does not offer superior results and can be dangerous, because it can cause potentially fatal complications and can promote

the development of drug-resistant infections.

Whether long-term antibiotics benefit patients with persistent symptoms of fatigue, musculoskeletal pains and neurocognitive dysfunction has been scrutinized using the highest level of scientific evidence: four placebo-controlled randomized trials do not support the use of long-term antibiotics as an appropriate treatment for Lyme disease.

Though some patients report feeling better after this treatment, these results are largely anecdotal and study after study has failed to demonstrate any benefit of long-term antibiotic treatment over placebo.

It should be noted that these randomized clinical studies reflected that approximately one-third of patients benefit from placebo. Hence, it is perhaps understandable why some patients and practitioners might mistakenly endorse long-term antibiotic therapy as helpful. This is precisely why it is important to perform well-designed clinical trials to distinguish if a therapeutic intervention has actual, beneficial effect in contrast to a resolution of symptoms which might merely happen on its own accord."

### **Treatment Guidelines for Lyme Disease**

The accepted guidelines for Lyme disease treatment are published by the Infectious Disease Society of America. The recommendation for treatment is 10 days to four weeks of antibiotics, depending on the clinical presentation.<sup>4</sup> In some cases, an additional four weeks of antibiotics are recommended. These guidelines are endorsed by CDC and NIH, and are also consistent with treatment guidelines in Europe and Canada. These guidelines were also subject to an independent review in 2008, and were found to be appropriate.<sup>5</sup> However, some people believe that these recommendations undertreat Lyme disease.

Guidelines ≠ Requirements: These treatment guidelines are nothing more than guidelines. They are not rigid protocols or a standard of care that must be adhered to. The standard of care is continually changing and evolving. There have been no actions taken by the Board of Medical Practice based on long-term antibiotic treatment for Lyme disease. Ultimately, any treatment plan should match the current scientific evidence with the individual needs of the patient, and reflect the important doctor-patient relationship.

## Why is there disagreement about treatment?

One reason is that people may have lingering symptoms even after being treated according to the Infectious Disease Society of America guidelines. According to CDC, approximately 10 to 20 percent of patients treated for Lyme disease with a recommended two to four week course of antibiotics will have ongoing symptoms of fatigue, pain, or joint and muscle aches. In some cases these can last for more than six months. Although often called chronic Lyme disease, this condition is more accurately called Post-treatment Lyme Disease Syndrome (PTLDS).<sup>6</sup>

The exact cause of PTLDS is not yet known, but it's likely that symptoms are the result of residual damage to tissues and the immune system that occurred during the infection. Similar complications and auto-immune responses have also been associated with other infections, including Campylobacter (Guillain-Barre syndrome), Chlamydia (Reiter's syndrome) and Strep throat (rheumatic heart disease). There is no evidence that antibiotics improve outcomes for people with these conditions.

#### **Diagnostic Testing**

Another area of disagreement is diagnostic testing. Some people believe that the tests currently recommended by CDC are not reliable and that many people with Lyme disease have negative tests. This is inaccurate. Like many other diagnostic tests, results are often negative early in the course of illness; these are called false negatives. However, test results are almost always positive in people who have had symptoms for a month or more. Testing is very helpful for diagnosing patients who have later stages of disease, such as Lyme arthritis. To date, there is no other more reliable test for early diagnosis.

There are laboratories that offer other types of tests for Lyme disease, but the methods they use have not been validated and their accuracy and clinical usefulness have not been adequately established. According to CDC, such unvalidated tests include capture assays for antigens in urine; culture, immunofluorescence staining, or cell sorting of cell wall-deficient or cystic forms of *B. burgdorferi;* lymphocyte transformation tests; quantitative CD57 lymphocyte assays; "reverse Western blots"; in-house criteria for interpretation of immunoblots; measurements of antibodies in joint fluid (synovial fluid); IgM or IgG tests without a previous ELISA/EIA/IFA.

## What is the Health Department doing about Lyme disease?

Fully informing Vermonters and health care providers about how to protect against, diagnose and treat Lyme disease is the best way to reduce the incidence and improve outcomes for people, regardless of one's view of testing and treatment.

#### **To keep Vermonters fully informed,** the Health Department offers:

- Website extensive information and educational resources, highlighted during tick season: www.healthvermont.gov (then search for Lyme disease or find it in the A-Z listing)
- Tick Tracker website launched in September 2013. This website displays a map of Vermont for people to indicate where and when they find ticks so that others can learn where ticks have been found in Vermont. Most importantly, it provides links back to the Health Department website so that people can get more information about ticks and tickborne diseases.
- News releases and media interviews with Health Department experts
- Be Tick Smart booklet: More than 30,000 copies, along with tick ID cards, distributed to date
- Community presentations
- A learning module for elementary school children is available for teachers to use.
- The second annual video PSA contest for high school students is underway.

The Health Department is also working with a Lyndon State College researcher on a tick and tickborne pathogen tracking project. Ticks are being collected from 12 sites around the state and tested to determine if they carry Lyme disease and two other tickborne diseases.

#### **To keep health care providers fully informed,** the Health Department offers:

- Website information and educational resources especially for health care providers at www.healthvermont.gov/prevent/lyme/provider.aspx
- Health Alert Network (an e-alerting system) updates health care providers about Lyme and other tickborne diseases. June 2012 update: <a href="http://www.healthvermont.gov/advisory/documents/060112\_lyme\_disease.pdf">http://www.healthvermont.gov/advisory/documents/060112\_lyme\_disease.pdf</a>
- The Health Department participates in continuing medical education sessions on tickborne diseases. In 2013, sessions occurred in April in White River Junction and in December in Rutland. Presenters included Health Department staff, infectious disease specialists from Fletcher Allen Health Care (FAHC) and community physicians who have treated patients for suspected chronic Lyme disease. Another session is scheduled for April 5, 2014 in Colchester. In addition, Health Department staff and FAHC infectious disease specialists presented on Lyme and other tickborne diseases at two sessions during the Health Department's Infectious Disease Conference in October 2013 in Burlington.
- The Health Department recently printed copies of CDC's quick reference manual for healthcare providers on tickborne diseases. This 30-page manual has been given out at the educational sessions for healthcare providers.

#### References

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http://www.idsociety.org/uploadedFiles/IDSA/Topics of Interest/Lyme Disease/Policy Documents/Lyme%20Disease%20Testimony-Global%20Health%20Subcommittee.pdf

<sup>&</sup>lt;sup>2</sup> The Infectious Diseases Society of America (IDSA) represents physicians, scientists and other health care professionals who specialize in infectious diseases. IDSA's purpose is to improve the health of individuals, communities, and society by promoting excellence in patient care, education, research, public health, and prevention relating to infectious diseases: http://www.idsociety.org/Index.aspx

<sup>&</sup>lt;sup>3</sup> Statement for the House Foreign Affairs Committee, Africa, Global Health and Human Rights Subcommittee's Hearing on Global Challenges in Diagnosing and Managing Lyme Disease — Closing Knowledge Gaps, Submitted by the Infectious Diseases Society of America, July 17, 2012.

http://www.idcociety.org/uploadedFiles/IDSA/Topics of Interest/Lyme Disease/Policy Documents/Lyme 20Diseases/20Testime

<sup>&</sup>lt;sup>4</sup> Gary P. Wormser, Raymond J. Dattwyler, Eugene D. Shapiro, et.al. 2006. The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America (exit VDH). Infectious Diseases Society of America. 43:1089-1134 (April 19, 2007)

<sup>&</sup>lt;sup>5</sup> Paul M. Lantos, William A. Charini, Gerald Medoff, Manuel H. Moro, David M. Mushatt, Jeffrey Parsonnet, John W. Sanders, and Carol J. Baker, Final Report of the Lyme Disease Review Panel of the Infectious Diseases Society of America. Clinical Infectious Diseases 2010; 51(1):1–5.

<sup>&</sup>lt;sup>6</sup> Centers for Disease Control and Prevention, Post-Treatment Lyme Disease Syndrome: http://www.cdc.gov/lyme/postLDS/index.html

<sup>&</sup>lt;sup>7</sup> Ibid